

**The Impact of Cultural Perspectives on Parents of their Children with Orofacial Cleft**

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## Introduction:

Facial clefting includes many types of congenital disorders. The most common are clefts of the lip and palate.

Approximately one in seven-hundred live births result in an orofacial cleft worldwide (Mossey et al., n.d.). Further, there are about 1/1600 babies born in the United States with a cleft lip and palate, 1/2800 have a cleft lip only and 1/1700 are born with a cleft palate only in the United States (CDC 2020). These statistics reveal that an orofacial cleft is a common occurrence that happens during early fetal development and can develop in different variations- cleft lip, cleft palate, cleft lip and palate.

In gestation, the lip forms in the womb around the seventh week of pregnancy. When the lip starts to form, tissues will fuse together. However, in the case of a cleft lip, the tissue does not fuse and creates a split. Depending on how much of the tissue forms can determine which kind of cleft lip results--unilateral or bilateral. Contrary to the lip forming around week seven, the palate forms around the ninth week of pregnancy. Like a cleft lip, a cleft palate is caused by the tissue of the roof of the mouth not fusing completely together. It is possible to have both a cleft lip and palate (CDC, 2020).

Although the cause of a cleft lip and/or palate is not known, some professionals have theories of potential causes that stem from genetic and environmental risk factors during pregnancy. Potential risk factors include smoking during pregnancy, being diagnosed with diabetes, substance abuse, and use of specific kinds of medicine. Recent research

reveals that risk factors such as these increase the chances of the child forming an orofacial cleft (CDC, 2020).

Despite what researchers have found, many people around the world have varying perceptions on the cause, impacting the person with an orofacial cleft in either a positive or a negative way. These beliefs and views are impacted by culture, religion, and place of origin. Perceptions from people who live in the western world are typically similar meaning they believe orofacial clefts occur from genetics and environmental factors. Views outside of the western world have a different take on the topic.

Current scholars studying families impacted by orofacial clefts worldwide express concerns of certain discriminations that lead to unequal treatment. Adeyemo and colleagues (2016) claim several cultures believe that orofacial clefts are due to a misbehavior considered to be sinful, which causes those with orofacial clefts to become alienated from their society. According to Perry & Stephen (2011), some Indian cultures believe orofacial clefts have occurred as a punishment of sins in previous lives. Because an unmarried girl is often seen as a burden to the family in Indian cultures, women born with orofacial clefts often struggle to find a husband and thus face additional hardships. Egyptian cultures suspect that being disobedient to the supernatural world is what creates orofacial clefts. Adeyemo and colleagues (2016) reported that two cultural groups in Nigeria, the Yoruba people and the Hausa people, were found to have different outlooks on orofacial clefts. The Hausa believed that the cause was due to an act of God, while the

Yoruba felt that the cause of orofacial clefts was due to an evil spirit. Although these two cultural groups seemed to contrast one another, the Yoruba families believe that those with orofacial clefts violated a religious principle and are being punished by God. Hereby, these individuals and their families become isolated from participating in their religion. Disconnecting people from their system of beliefs causes them to feel disgraced and unwanted which can lead to serious psychological problems. Although there are cultures who hold these beliefs, not all cultures have a negative perception of orofacial clefts and view them as a sin. There are many cultures who see this as a gift from the supernatural world. This type of positive mindset and attitude raises the child's confidence and can set them up for success in life.

No matter the belief in what causes orofacial clefts, what is more important is the future of the child. From a young age, a child's environment, whether it is positive or negative, can shape their future.

Psychologically, how a primary caregiver perceives their child or predicts their child's future before it happens can play a role in whether that child grows up with a high quality of life. For instance, if a primary caregiver believes their child cannot sustain a good quality life or believe their child won't be successful in the future, this type of mindset will psychologically affect the child. If the child mimics their primary caregivers beliefs, it is possible they won't have a high quality life. It is important that primary caregivers keep their child's future at the center of their decision making in

order to help their child have the highest quality of life possible.

In certain situations, depending on the socioeconomic status, some primary caregivers may feel concerned about finances for doctors visits and future surgeries, which could impact how they interact with the child. These primary caregivers feel that they cannot provide for their child's needs in a way that is best for them. This can place the primary caregiver into a position of not feeling worthy enough to care for a child and can continuously affect their emotional state. According to Searle & Waylen (2019), primary caregivers may feel responsible for their child's orofacial cleft, become extremely anxious about their child's future success, or become overwhelmed with the challenges of feeding their child. Depending on how their culture feels towards an orofacial cleft, the primary caregivers may become ostracized by their neighbors due to how the child physically looks. Overall, it can be extremely difficult to remember the importance of their child's future because of these thoughts that overwhelm their minds.

The higher level of education the primary caregiver has could shape their beliefs and ways they interact with the child, helping combat anxieties they may feel about their child's orofacial cleft. Different levels of education could change the way a primary caregiver perceives the child with an orofacial cleft. If a primary caregiver has higher levels of education and hence, a high quality of life, they may not be concerned about the environment that their child will have growing up. They may feel confident in their child's future success and feel that

the child will also have access to higher levels of education. This notion early on can impact how the primary caregiver interacts with their child because they will prepare them as much as possible to be successful.

As a result of having enough finances from higher education, these primary caregivers may also be informed from the best cleft palate teams in their area about their child's craniofacial anomaly and have access to the best doctors who work with these teams. In addition, primary caregivers who have higher levels of education may feel more confident in themselves as people and are willing to reach out to more cleft palate teams and doctors to get multiple opinions and surgery options. This determination to reach out to more clinics and doctors can stem from the fact that the primary caregiver wants their child to be successful. Regardless of the education level, the way a primary caregiver interacts with their child can nurture the child's emotions and their self-image as they mature.

Despite the fact that educating the primary caregiver about their child's condition is extremely important, socioeconomic status often determines the quality and quantity of the education and care they receive. Primary caregivers of a lower socioeconomic status may not be able to afford quality care for their child, which could further play a role in the child's development. Furthermore, this may correlate with how they perceive their child in a negative way because of the lack of access to a quality cleft team.

In contrast, people of a higher socioeconomic status will have the ability to

afford high quality care and support from a cleft team. If necessary, multiple surgeries are more easily accessible as well. The benefit of reconstructing the orofacial cleft to the greatest extent possible can allow for a greater physical and mental health of a child leading them to have more confidence in themselves. Having a cleft team who is supportive and very involved is important for the child's development and for the primary caregivers' education on this issue.

Initially, it may seem that the main issue those with orofacial clefts encounter is their physical limitations. However, van der Plas and colleagues (2013) declare feelings of shame due to social judgement run far deeper than one's own appearance or physical ability. Society assumes that these people are at a disadvantage regarding their physical craniofacial anomaly. Despite what people see, this is very superficial. Because of the remorse, those with orofacial clefts are at social disadvantages, causing them to have the lack of ability to form relationships with others. According to Speltz and colleagues (2016) the way in which the caregiver views their child's orofacial cleft is a factor in the maturation of the child's emotional well-being. In illustration, if the culture around the child is affirming that their orofacial cleft is abnormal, this causes the child to grow up with a lack of self-worth. The detrimental effects on the child from their surrounding culture begin at infancy. After a child is born, the kind of attachment they develop with their primary caregiver can affect their quality of life for the rest of their lifetime. Insecure attachment consequently is what some children with an orofacial cleft face. This phenomena plays

an immediate factor in their psychological well-being because the bond between the primary caregiver and child is taken over by fear. A common cause of the insecure attachment is believed to be the lack of facial expressions the child with orofacial clefts can make displaying them as less responsive in social situations. Insecure attachment may stem from the primary caregivers not knowing how to interact with their child because of the child's lack of ability to make facial expressions (Speltz et al., 2016). Some primary caregivers immediately have the mindset that they won't know how to care for a child with a cleft lip or palate hindering the child's development. This is proof that placing a stigma on an individual with an orofacial cleft can affect their success and how they grow up.

Negative perceptions and doubts primary caregivers feel towards their child with an orofacial cleft can leave a long term impact on the child. The child may feel as if they are a disappointment or do not have a steady future ahead of them because of these negative perceptions. Although these negative perceptions can potentially have a long term effect, it is not the only factor that can affect a child.

Physically, children with orofacial clefts are more prone to different health and speech problems. A few of these health and speech issues include hearing, speech, eating, and dental problems (Cleveland Clinic, 2020). Orofacial clefts can also cause children to have more fluid build up in the middle ear, making them more susceptible to constant ear infections. Untreated or delayed treatment of ear infections can cause

significant hearing loss affecting the child for life. These children are also more susceptible to cavities and may have displaced or missing teeth. Orofacial clefts can result in a fault in the alveolar ridge, affecting the growth of teeth. This ultimately can lead to premature loss of the canine teeth (Cleveland Clinic, 2020). Encountering many dental problems will impact the child's speech and ability to eat. Missing or misaligned teeth are going to affect how the child produces sounds. Besides dental issues, craniofacial anomalies can cause eating disorders. With an unfused palate, food and liquid can easily go into the mouth and come back right through the nose (Cleveland Clinic, 2020). Because swallowing requires the palate to remain closed, food and liquid will not be able to travel down the pharynx if there is not a fused palate. Eating problems can easily be solved through surgery or swallowing techniques but if this problem is not solved it is possible that eating disorders can result from improper feeding.

A child with an orofacial cleft can have issues with speech and language skills. Oftentimes, people assume that the severity of the orofacial cleft is an indicator of the child's development in speech and language. However, this is not the case and is not always an indication of a child's future speech and language skills (Cleft Lip and Palate Association, 2021). It is never evident of how an orofacial cleft impacts speech development until the child begins to speak. A child with an orofacial cleft might have problems with speech or language due to the many surgeries. As a result, they lose a critical point in their lives to learn speech

and language. However, surgeries may help a child by fixing structural problems and further aid the child in producing their speech sounds as they mature (Cleft Lip and Palate Association, 2021).

In some cases, a child may not feel confident in themselves as communicators because of how their primary caregiver views their orofacial cleft. The primary caregiver may not feel confident in their child's speech and language development because of their socioeconomic status and are not able to afford the proper medical care. There may not be a speech-language pathologist in low income areas to have access to if a problem arises, or a cleft palate team to give care to the child and family. Therefore, the child may lack certainty in their speech because of the lack of support and resources. A child with an orofacial cleft might not feel confident in their speech because of how they physically look and do not like attention being brought to them. Fears of bullying may stem from the fact that their speech or language may not be like everyone else around them.

The rationale of this study is to characterize the correlation between positive views of orofacial clefts and a successful life, as well as negative views and a burdensome life. This will allow a discovery of any similar trends among cultural and socioeconomic groups regarding orofacial clefts. Because of the high prevalence of craniofacial anomalies, it is important to increase the awareness of issues that could arise regarding the mental and physical health of the child, as well as the hardship the primary caregiver could endure as a result of their child's orofacial cleft.

Depending on the socioeconomic status as well as their geographical location, different primary caregivers may have various perceptions and knowledge on their child's orofacial cleft. Indeed, this research revealed to us how socioeconomic status and geographic location plays a role in their beliefs. Research was primarily focusing on the two research questions posed: 1. How does a person's socioeconomic status affect their confidence in their child's future? 2. Does the perception of clefting correlate with where the primary caregiver currently lives or their origin?

### **Methods and Procedures**

Primary caregivers who have children with orofacial clefts have created facebook groups in order to inform and support other primary caregivers in similar situations. Members of these support groups bond over the hardships that their children have endured through surgeries and life. All members of these groups range in race, socioeconomic status and location. Ages vary in the children of these primary caregivers in these groups. A survey link was sent into these groups where participants could anonymously and voluntarily take the survey (refer to Appendix A). Before the survey was taken, volunteers read an information template consisting of a confidentiality statement as well as instructions. Survey questions consisted of demographic information such as race, age, gender, socioeconomic status. Questions also focused on rating the confidence of their child's social, speech, and academic development as well as likelihood of their child getting bullied,

succeeding in the future and how financially well off they will be. Ratings were based on a scale of one to five with five being most confident/highest and one being least confident/lowest. For instance, a participant rating their confidence in their child's future success at a five would mean they have the most confidence in their child contrary to a ranking of one meaning they are least confident in their child's future success. These questions target the psychological aspect of the primary caregiver. All participants ranged in race, socioeconomic status and location

## Results

The number of participant responses in this research study was twenty nine in total. Responses ranged from all over the U.S as well as internationally. Twenty two of those responses were from people who currently live in the U.S while seven responses were from people who live internationally. Of all of the participants, twenty were female making this the majority of respondents. Twenty two of the participants were White, one was Black, one was Central Asian, two were Hawaiian/Pacific Islander and three listed more than one race.

Data obtained from the survey revealed certain trends between the array of responses that were received. These trends allowed for grouping responses together and analyzing similarities and differences between each. Listed below are commonalities among results.

Findings of the research show that every primary caregiver who had a child

with an orofacial cleft under the age of three rated the confidence of their child being successful in the future at a three or lower. On a scale of one to five, three means the participants' confidence in their child's future success is average. Therefore, the trend of the confidence level being three or lower demonstrates an average and below average level of confidence. With the rating scale being listed from one to five, with five being most confident, it appears that primary caregivers with a younger child may have doubts about their child's future as they grow up. A factor to this could possibly relate to the primary caregiver being unaware of how children with orofacial clefts can grow up regularly.

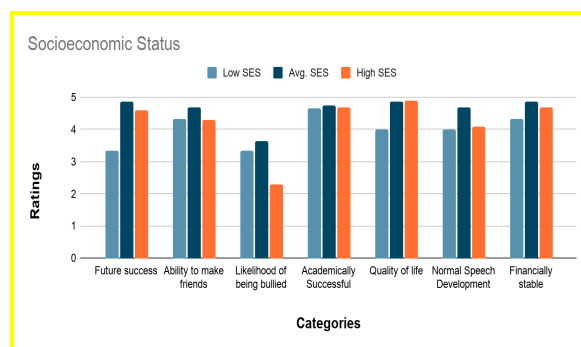
Primary caregivers with children older than three years old, primarily children who have already experienced grade school, rated their confidence in their child to have great future success at a higher ranking. Theoretically, the reasoning behind this could be that the primary caregiver has experienced their child successfully socializing with others or learning in school. This finding leads to supporting evidence that if the primary caregiver were to have another child with an orofacial cleft, the second child would most likely be perceived with more confidence than the first child. The reason is because the primary caregiver has now experienced what having a child with an orofacial cleft is like and how they can grow up almost the same as any other child.

In the ratings of the likelihood their child will be bullied, on a scale of 1 being low and 5 being high, high rankings came from primary caregivers who claimed to be

below average or average financially. There were no primary caregivers in the above average SES range who believed their child had a high chance of getting bullied. This stems from the possibility that people from a high socioeconomic status have more access to afford multiple surgeries in order to reconstruct the craniofacial anomaly into a way that is pleasing to them. However, bullying transpires in any environment. Most trends, as does this research, show that bullying is unfortunately a theme that is most common in low socioeconomic environments.

It also is worth noting that there were correlations in the responses between levels of education in socioeconomic groups. Every primary caregiver who claimed to have a low socioeconomic status only received a high school diploma as their highest level of education. Furthermore, out of these eleven people who have high school diplomas as their highest level of education, only one person claimed that they believe “genes” cause craniofacial anomalies.

Contrarily, people who claimed to be of average socioeconomic status and high socioeconomic status all had bachelor’s, master’s, and doctoral degrees. Out of the eighteen people in these groups, eight of them claimed “genes” was the cause. Although genes are not the cause of an orofacial cleft, primary caregivers with higher education might have selected these answers because some birth defects are caused by genes.



**Figure 1.** Bars represent the mean rating of each socioeconomic group's answer to the parental concerns section in the survey questions. Refer to appendix A.

A review of the research responses has allowed identification of patterns among different SES groups in this study. Figure 1 focuses on responses from different SES groups and highlights the mean rating of each response in the survey. The questions focused on are listed under the bar graphs in figure 1 and are as follows: 1. Confidence in child's future success. 2. Confidence that the child will make friends. 3. Likelihood of child getting bullied or embarrassed. 4. Confidence that child will succeed academically. 5. Quality of life child will have growing up. 6. Confidence that child will be able to obtain normal speech development. 7. Confidence that child will be able to find a financially stable career.

Research shows that the average rating for participants falling in the high SES category believed their children had a low chance of getting bullied with an average rating of 2.3. Given this information, it is clear that the primary caregivers felt the risks of bullying were greater in the low and average SES categories than primary caregivers in the high SES. This implies that people who are financially well off are most likely sending their children to private schools or schools

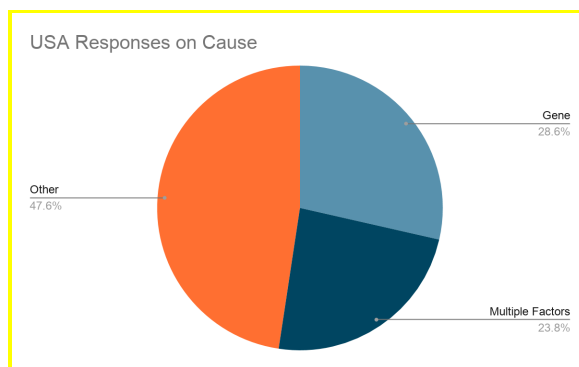


where bullying is not as high as other low budget schools. Private schools are known to have less students than a public school meaning there are less children likely to bully others. While this is an assumption from the data results, it is an important matter to think about.

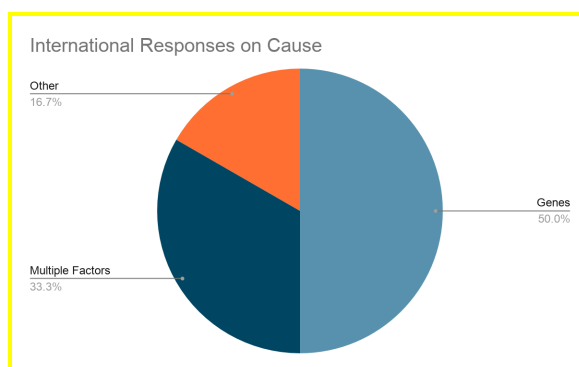
Data results from figure 1 also revealed that participants in the low SES section rated their confidence in their child's future success lower than the other SES sections. The same was also true for quality of life and normal speech development. The mean for future success in the low SES section concluded to a rating of 3.33 while average and high SES concluded to a mean rating of 4.875 and 4.6 in that order respectively. Even with the difference between the sections being slightly over 1, this is a huge difference in confidence levels that the SES groups have in their child. Future success and being financially stable can have an association. Families may feel their child may not be as successful because of their financial situation and inability to provide them with enough medical care. This statement stems from the finding that ratings for confidence that their child will be financially stable were higher in the average and high SES groups than the low SES group.

While some of the ratings varied among the different SES groups, each of these groups shared a close mean rating in the confidence their child would be able to succeed academically. This reveals that the participants realize that orofacial clefts do not affect cognitive function and allows academic success. The confidence could also emerge from the primary caregivers'

determination to keep their child from falling behind academically. Keeping a report of their child's academic success will allow the primary caregiver assurance that their child is not experiencing delay in their educational endeavors.



**Figure 2.** Mean number of responses from USA participants on what they think the cause is. Percentage refers to the percent of participants who answered each option.



**Figure 3.** Mean number of responses from international participants on what they think the cause is. Percentage refers to the percent of participants who answered each option.

Each pie chart (figures 2 and 3) demonstrates the difference between what international participants and what U.S participants believe the cause of orofacial clefts are. Figure 2 refers to responses recorded from the participants living in the U.S while figure 2 demonstrates responses from participants living internationally. Three options referring to the cause of an orofacial cleft were given to the participants: genes, multiple factors and others. Results

show differences in responses between national and international participants.

Patterns from results reveal that more international participants feel that genes are the cause of orofacial clefts in comparison to participants who live in the United States. Although genes are not the cause of a cleft that occurs, it is significant to note that 50% of international participants selected this answer while only 28% chose this answer in the United States. This prominently chosen answer selection could mean that primary caregivers outside of the United States have been misinformed about the formation of their child's orofacial cleft. Further research would need to be conducted in order to get a better understanding of the large number in this response category.

In deeper analysis of the question regarding the cause, more international participants selected multiple factors as a cause in comparison to those from the United States. The category of "multiple factors" could cover a multitude of rationales. The percentage for international primary caregivers was 33% while the percentage for national primary caregivers was 23%. This significant difference could indicate that primary caregivers internationally feel unsure about one specific cause, and believe that there are many reasons for their child's orofacial cleft.

It is interesting to note that in viewing these charts, half of the international participants selected genes while half of the national participants selected other. Half of the number of responses from each group felt similar to those in the same category. Further research would need to be conducted in order to

break down the international grouping into country or region to determine more specific perceptions.

### **Discussion:**

Moving forward, future research would consist of acquiring more responses. Working with cleft palate organizations or through cleft palate teams would allow for more surveys to be sent out and more responses to be acquired. In order to get a more accurate representation and discover more precise themes within the research data, surveys would need to be sent out internationally since most of over half of the current research data are from participants living within the United States. By collecting data from other countries, there will be a higher chance of obtaining a wider span of views as well as comparing and contrasting views of participants around the world. This allows identification of different views that different cultural groups have when it comes to orofacial clefts.

The main strength of this research was the ability to identify differences between different SES groups and their confidence levels in their children. These findings allow for more future research concerning why primary caregivers in lower SES groups rated their child with a higher chance of getting bullied than primary caregivers did in the average and high SES groups.

An additional strength was the connection between causes of clefting depending on where the participant was from. USA participants mostly chose "other" as the cause while international participants mainly chose "genes". For

future research, this finding allows us to focus on why USA participants chose “other”. As future surveys are sent out there will be a section allowing for participants to write out exactly what other cause they think it is.

In contrast, there were some limitations in this study that will be reevaluated and considered in future research. One limitation was the amount of participants in the study. With there being only twenty nine responses to the surveys, there is an increased change for margin of error. Analyzing the data from a larger group of people would allow for a more precise dissection of the correlations between the psychological, socioeconomic, education status and cultural perspectives.

Another limitation to the study is the lack of diversity in responses. The responses primarily came from white females from the USA. The responses received could be a result of the participants coming from Facebook groups. This lack of diversity limits the research and prevents any strong findings in the confidence the primary caregiver has in their children as well as what they believe the cause of orofacial clefts are.

A final limitation to this study would be that “multiple factors” was an option instead of having an option for “unknown” as the cause. If “unknown” was an answer choice, correlations could have been found between national and international participants to see if they knew the true answer. In future research on this topic, this option will be an additional answer choice for a better understanding of what the

primary caregivers truly believe because of this more specifically targeted question.

## Conclusion

In summary, the survey responses revealed that socioeconomic status, education level of primary caregivers and geographic location play a role in the perception of their kid with an orofacial cleft. Additionally, primary caregivers with a lower socioeconomic status were more likely to have less confidence in their child's future than more financially stable primary caregivers. Geographic location played a bigger role in what they believe to be the cause of orofacial clefts rather than their perception of their child. International primary caregivers mainly believed genes were the reason for orofacial clefts while responses within the U.S thought there were other factors that caused this. With further research and a more diverse as well as a larger number of participants, a more accurate analysis can be done.

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## Appendix A

### Survey Questions

#### **DEMOGRAPHICS**

Ethnicity: a. Hispanic or Latino b. Non-Hispanic or Latino  
 Race: a. White b. Black/AA c. Asian d. Native American e. Hawaiian/Pacific Islander f. Other  
 Sex: a. Male b. Female  
 Gender identity: a. Male b. Female c. Non-binary

#### **ADDITIONAL DEMOGRAPHIC INFORMATION**

Primary Caregiver: 1. Both parents 2. Mother 3. Father 4. Grandparent 5. Other relative 6. Foster care 7. Other

Marital Status of Primary Caregiver: 1. Married 2. Never married 3. Divorced 4. Widowed

Primary Caregiver's Country of Origin: \_\_\_\_\_

Primary Caregiver's Highest Educational Level: \_\_\_\_\_

Have any of your family members had a cleft palate? 1. Yes 2. No

Have you known anyone with a cleft palate? 1. Yes 2. No

Primary Income Provider's Occupation: \_\_\_\_\_

Estimated SES: 1. Low 2. Lower Middle 3. Middle 4. Upper Middle 5. High

#### **CONCERNING THE CHILD**

Age of First Visit to the Cleft Palate Team: \_\_\_\_\_

Age of Cleft Palate Surgery: \_\_\_\_\_

Primary Language of the Home: 1. English 2. Other (specify) \_\_\_\_\_

Do you live in a bilingual household? 1. Yes(specify)\_\_\_\_\_ 2. no

Religion of the Home (if any): \_\_\_\_\_

Number of siblings in the home: \_\_\_\_\_

Number of people living in the home: \_\_\_\_\_

#### **PARENTAL CONCERNS (scale: 1 low – 10 high)**

Confidence in the social development of child after surgery 1 2 3 4 5 6 7 8 9 10

Willing to join a cleft palate support group for other caregivers like you 1 2 3 4 5 6 7 8 9 10

Confidence that your child will be able to make friends 1 2 3 4 5 6 7 8 9 10

Confidence your child will be able to succeed academically 1 2 3 4 5 6 7 8 9 10

Quality of life you believe your child will have growing up

1 2 3 4 5 6 7 8 9 10

Confidence that your child will be able to obtain normal speech development

1 2 3 4 5 6 7 8 9 10